

Ethical Challenges of Big Data in Public Health

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Digital epidemiology, also referred to as digital disease detection (DDD), is motivated by the same objectives as traditional epidemiology. However, DDD focuses on electronic data sources that emerged with the advent of information technology. It draws on the explosive growth in mobile devices, and online sharing platforms, which constantly generate vast amounts of data containing health related information, even though they are not always collected with public health as an objective. Furthermore, this novel approach builds on the idea that information relevant to public health is now increasingly generated directly by the population through their use of online services, without their necessarily having engaged with the health care system. By utilizing global real-time data, DDD promises accelerated disease outbreak detection, and examples of this enhanced timeliness in detection have already been reported in the literature. The emergence of DDD promises tangible global public health benefits, but these are accompanied by significant ethical challenges. While some of the challenges are inherent to public health practice and are only accentuated by the use of digital tools, others are specific to this approach and largely unprecedented. They span a wide spectrum, ranging from risks to individual rights, such as privacy and concerns about autonomy, to individuals' obligations to contribute to the common good and the demands of transparency and trust. We have grouped these concerns under the headings of context sensitivity, nexus of ethics and methodology, and bootstrapping legitimacy. It is vital that engagement with these challenges comes to be seen as part of the development of DDD itself, not as some extrinsic constraint. We intend this paper to be a contribution to the development of a more comprehensive and concrete ethical framework for DDD, one that will enable DDD to find an ethical pathway to realizing its great potential for public health.